

September 24, 2014

To: Representatives John Kissel, Mary Mushinsky and the other members of the Program Review and Investigations Committee

My name is Lisa Freeman and I am the very proud parent of a young adult with autism. He is a smart young man with great potential, but he needs support in certain areas that include employment, social skills and some skills of daily living – and he needs them today. He needs support so that he can participate in a healthy way and contribute many wonderful things to his community and his state. He needs support so that he can share his life comfortably with his peers and so that he can find happiness and fulfillment in his own life, as we each seek to do. He needs support so that he can access the personal satisfaction of being able to say, at the end of a day, that whatever he did that day was a job well done! He needs continued support because his public school education ended well before he was fully transitioned to the next stage in his life.

During the years of public school attendance, our children are entitled to receive certain support services because of the Individuals with Disabilities Education Act (IDEA). The day that they leave the school system by age 22, adult services become almost unavailable, except to the most profoundly impacted by autism. For those who are high functioning and who do not have an intellectual disability, there are especially few supports – these individuals not only fall through the cracks, they fall into an abyss! The Department of Developmental Services has a program – the Autism Waiver Program – that is set up to provide funding for those individuals with autism who qualify for Medicaid and are not intellectually disabled. I believe that it was established with people like my son in mind. But it is minimally funded and right now there are a few hundred qualifying individuals on the wait list and only around 100 receiving services. My own son has been on this list for well over TWO years and as of this past March 2014 was number 68. Who knows how many more years he will remain on the wait list? This is not acceptable! He needs support services now and each day we don't provide them to him, valuable time is lost. He has so much potential!

He is currently working with a counselor at BRS who has paired him with a job coach through BRS. My son and the job coach have been working together to find an appropriate job. But I have been told that my son will need ongoing support for more time than BRS is able offer in order to maintain a job. BRS does not have the funding for this – they are a short term agency. Apparently, as has been explained to me, they have programs for some clients with funding from other sources. But because my son has been approved for services from DDS through the autism waiver program and does not qualify for services through another agency, and even though HE IS ON A WAIT LIST and receiving NOTHING FROM DDS IN THE MEANTIME, he is not eligible for any of the funding for support that BRS might otherwise offer. The result is that I have been asked to personally guarantee that I will fund ongoing support needed to maintain

employment for my son or BRS cannot work with him and place him in employment. How unfair is this?

The ironic thing is that if he does enter the workforce and earn salary and pay taxes then he would be needing less of other funding, he would be contributing to the system and he would be living a healthier life, in the broad sense of healthy. How does it make sense, on any level, to underfund support services that save money and lead to less demand on the system in the end? Are we, through short-sightedness and lack of understanding, contributing to higher system costs for support of co-morbid conditions that could be avoided?

According to the World Health Organization, "Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community. In this positive sense, mental health is the foundation for individual well-being and the effective functioning of a community...."¹ Because my son has autism is why he needs support to achieve this state of well-being. And we well know that mental health issues correlate with higher costs all around. Are our residents with autism not entitled to the same support that is offered through DMHAS to residents with mental health and addiction issues or through DDS to those with an intellectual disability?

Your committee is charged to examine "state government programs and their administration to ascertain whether such programs are effective, continue to serve their intended purposes, are conducted in an efficient and effective manner, or require modification or elimination." I wish to suggest that the Autism Wavier Program is clearly needed even and especially in tough economic times. However, without modification to fully fund it, it is not reaching nearly enough of the intended recipients. Furthermore, **due to the way other agency's policies are written**, by approving and then placing residents on a DDS Autism Wavier program wait list, it is obstructing them from receiving other minimal funding that might be available in the meantime.

By not funding appropriate support for Persons with Autism Spectrum Disorders we are not giving these residents of Connecticut a chance to appropriately contribute to our State's community and to lead decent, fulfilling lives. Shame on us if we deny these wonderful men and women the funding that they need.

Respectfully submitted,

Lisa Freeman (Parent of a young adult with autism)

¹ "Mental Health." *WHO*. World Health Organization, 2014. Web. 22 Sept. 2014. <http://www.who.int/topics/mental_health/en/>.

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